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Literature overview highlights lack of paediatric donation protocols but identifies common themes that could guide their development

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Short title: Overview of paediatric donation protocols.

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ABSTRACT

Aim: Paediatric donation is a unique and extremely sensitive process that requires specific knowledge and competencies. Most countries use protocols for organ and tissue donation to ensure optimal care for the donor and family, but these mainly focus on adults. However, the donation process for children differs from adults in many ways. An overview of the literature was performed to identify protocols for the paediatric population.

Methods: PubMed, Web of Science, Embase and the Internet were searched up to March 2016 for papers or other sources in English related to specific organ and tissue donation protocols for children and neonates. This comprised title, abstract and then full-text screening of relevant data.

Results: We included 12 papers and two electronic sources that were mainly from North America and Europe. Most discussed donations after cardiac death. The recurring themes included identifying potential donors, approaching parents, palliative care and collaboration with organ procurement organisations. Most papers called for paediatric donation policies to be standardised.

Conclusion: Scientific publications in English on paediatric donation protocols are very scarce. No comprehensive paediatric donation protocol was found. We identified several recurring themes in the literature that could be used to develop such protocols.

Key words:

guidelines; organ donation; paediatric; protocol; tissue donation

Key notes:

Paediatric donation is a very sensitive process that requires specific knowledge and competencies and we carried out a literature search for paediatric donation protocols

No comprehensive paediatric donation protocols were found, but recurrent themes in publications were identifying potential donors, approaching parents, palliative care and collaboration with organ procurement organisations.

These themes could provide a good basis for the development of comprehensive paediatric donation protocols.

BACKGROUND

The waiting list for children who need an organ or tissue transplantation is constantly increasing and the demand for organs continues to exceed supply. Most of them need small organs or tissues from paediatric donors and every year children on waiting lists die before they receive a transplant (1). Despite this, there is little data about the procedures for organ and tissue procurement in paediatrics (2). Paediatric donors are predominantly found among children admitted to a paediatric intensive care unit (PICU), who die because of trauma, near drowning, cardiac arrest or neurological disorders. Siebelink et al (3) showed that each year 11% of the children who died in eight Dutch PICUs were potential organ donors, but the actual number of paediatric organ donations carried out in The Netherlands according to the 2015 report from the Eurotransplant International Foundation was around five to eight per year in recent years (1). That means that, on average, each Dutch PICU handled one donation or fewer each year.

The death of the child is almost always unexpected and the resulting time pressure makes the donation process very sensitive. Moreover, we know that the circumstances surrounding a request for organ donation influence parental consent (4-7). Widely recognised barriers to donation are: failure to discuss donations with families, failure to identify potential donors and failure to notify the organ procurement organisations (8-10). The potential interventions to reduce barriers focus on optimising the identification of potential paediatric donors and improving consent procedures (11). As a consequence, professionals have to be highly competent when discussing the possibility of a donation to the family.

The rarity and complexity of paediatric donations make it very difficult for healthcare providers to become competent and comfortable with the donation process. One way to support the quality of such a rare intervention is to have excellent protocols available for all disciplines involved in the process. Optimising the donation process could potentially reduce waiting list deaths. We wanted to know which donation protocols, specifically aimed at the paediatric population, were already available for practitioners, parents and others. The aim of this study was to identify and analyse the similarities and differences between protocols published in English.

METHODS

We searched the PubMed, Web of Science and Embase electronic databases. Our search strategy combined terms that described organ and tissue donation protocols that were specific to children and neonates (Appendix 1). All the terms were in controlled and free text.

We searched for full-text scientific papers in English and their inclusion was not limited by time restrictions or study methodology. The reference lists of the relevant papers were screened for further sources. In addition, we searched the Internet for consensus statements by paediatric intensive care professional bodies, published in English, to make sure that all relevant electronic sources of knowledge on this topic were included.

All references were screened by title and abstract and selected references were retrieved for full text screening. Finally, two authors discussed the selected papers and decided whether to accept or reject them for this review.

The selected papers and statements were divided by topic using extraction forms. The extraction forms included the title, authors, year of publication, country, design and relevant data, such as the protocol or policy description or protocol recommendations.

RESULTS

The first search on 18 February 2016 yielded 595 references in PubMed, 298 in Web of Science and 586 in EMBASE. Due to the small number of eligible references, we decided to

conduct a second search on 15 March 2016 using an adjusted search strategy in PubMed.

Both search strategies are reported in Appendix 1. This search yielded 1,148 additional references. Duplicates were removed from the 2,604 references and others were excluded based on their titles and abstracts.

Full text screening was performed on 25 references and a further 13 were excluded after screening. Finally, we included 12 papers in the literature overview.

Our Internet search resulted in two electronic consensus statements by professional bodies related to paediatric organ and tissue donation that were not published in biomedical journals.

Characteristics of the papers

We reviewed 12 papers that discussed organ and tissues donation protocols. Of these papers, seven discussed donations after cardiac death protocols, four discussed both donations after cardiac and brain death only just discussed brain death protocols. In addition, the papers differed significantly in their design. Most papers originated from centres in North America and only two papers were from Europe. Table 1 presents the general characteristics of the papers. There were seven recurring themes that were identified in all of the papers and these are presented below. A summary of these themes, together with other key findings, are presented in Table 2.

Identification and timely referral of potential donors

The majority of the papers emphasised the importance of the first step in the donation process: timely identification of potential donors in the PICU and timely referral to an organ procurement organisation to increase organ donation rates (9,10,12-16). The need for improved identification and timely referral of potential donors in neonatal intensive care units (NICUs) was highlighted in two papers (14,17). Antommaria et al (12) studied donation after cardiac death policies at children's hospitals and also studied donors. Most of those hospitals applied clinical indications and restrictions to potential donors such as not brain dead, ventilator dependent, pharmacologically dependent and imminently dying. Some used

age restrictions and the minimum ages ranged from 36 weeks of gestational age to 60 months. The minimum weight restriction for newborn infants was 10kg.

Approach of parents and family

Most authors agreed that the process of delivering the bad news about the child's anticipated death and the question of organ donation must be separated (10,12-16,18-20).

The majority of the authors referred to donation as an opportunity for grieving families to obtain solace, hope and comfort during a terrible time (13-15,18,21). Sarnaik (14) also emphasised the importance of supporting the patient's and family's interests without considering any potential benefit to others. In the same context, the American Academy of Pediatrics pointed out that the decision to donate is one made by the family, not by physicians (10). The European Society for Paediatric and Neonatal Intensive Care suggested a collaborative discussion about donation with the family with both the PICU team and organ donation team or just the organ donation team if the PICU team agreed to this (22).

Collaboration with the organ procurement organisation

The collaboration with the organ procurement organisation professionals during the donation process was considered to be one of the most relevant themes in the majority of the papers, as this increased the chances of successful donation (9,10,12-14,16-20). For example, some authors recommended early participation of trained organ procurement organisation professionals, who discuss organ donation, obtain informed consent and support the family during and after the donation process (10,13,14,19). One of the advantages of this early involvement, as suggested by Mathur et al (17), is that the team can assist in evaluating the medical suitability of potential donors.

Informed consent

The authors of all papers agreed that families should provide consent for certain types of procedures, including pre-mortem procedures and should be able to withdraw from the process at any time (12,14,15,18).

Palliative care

Palliative care for potential donors and support for the donor family was an essential theme in many of the papers (9,12-17,20,21). Some authors specifically focused on the importance of comfort of potential donors and on specific interventions and therapies to obtain the required level of comfort (13,14). Antommaria et al (12) reported variations in the use of generic pre-mortem medication or procedures in paediatric practice (12). Curley et al (15) emphasised that some pre-mortem procedures may improve successful transplant organ survival, but they did not specify which procedures. Kolovos et al (13) added that some palliative care medication, for example heparine or vasodilators, could harm the donor. Their opinion was that harmful medication that could shorten life should never be used. The UK National Health Service (23) published optimisation care bundles for paediatrics on their website. Those bundles include recommendations for optimal cardiovascular, respiratory, fluid and metabolic management and also for thromboembolic prevention, the use of lines, drugs and other related areas.

The following topics were reported to be of particular relevance to the palliative care of potential donors: preparing the parents for donation, including full information about the process of the child's death and a private space and a liaison for the child's family after the child had been taken into the operating room (21). Kolovos et al (13) agreed that in donation after cardiac death cases, families should have the opportunity to be with their child at the time of death. Other authors (14,16) observed that there was a lack of knowledge about what constituted appropriate care and aftercare in this context. Nevertheless, they recommend that all aspects of the care of the body should be carried out according to the family's wishes. Finally, Mathur et al (17) called for palliative care protocols for potential donors in the NICU.

Declaration of death

The American Academy of Pediatrics and European Society for Paediatric and Neonatal Intensive Care emphasised that the accurate and timely declaration of brain death was essential to ensure successful donation(10,22). The neurological criteria for brain death were

clearly described: complete loss of consciousness, no spontaneous movements, no reaction to stimuli, no function or reflexes of the cranial nerves and no spontaneous breathing during apnoea testing. Brain death can be diagnosed in term infants from 37 weeks of gestational age (14,23).

The circulatory criteria for declaration of death and the waiting periods for a declaration of death in donation after cardiac death cases varied from less than two minutes and longer than five minutes. (13,14,18). There was also a considerable difference in the potential methods and criteria to determine death, for example the absence of heart sounds by auscultation, palpable pulse, unresponsiveness, absent arterial pulse and apnoea (12,13,20). Weis et al (20) called for the standardisation of those methods. Some authors reported a maximum waiting time for organ recovery following the withdrawal of life-sustaining treatment and these ranged between 60 and 120 minutes (12,14,20). In addition, Sarnaik (14) reported that if circulation did not stop within a determined period, the patient could no longer be considered a donation after cardiac death candidate and end-of-life care should continue as usual. Considering the mixed recommendations, as stated above, the Transplantation Society has called for global standardisation of the criteria for diagnosing death for organ donations, both by neurological criteria and by circulatory criteria, including the waiting period and the terminology used to describe death (9).

Staff education

Only a few authors discussed specific staff educational needs for paediatric donation protocols. However, the American Academy of Paediatrics (10,19) strongly emphasised the need for regular staff training, which should include medical, ethical, social, cultural and religious issues related to the potential donor. The Transplantation Society (9) specified that training in end-of-life care and organ donation processes should be provided to healthcare professionals from all specialisations and disciplines who may be involved in the care of potential or actual donors, not just critical care professionals. Finally, a study by Siebelink et al (16) that was published in 2012 reviewed the relevant literature and concluded that no education programmes for professionals existed at that time.

DISCUSSION

Papers published in English that discussed protocols for paediatric donation were scarce. We only found 12 papers and two electronic consensus statements by professional bodies related to paediatric organ donation. Despite the limited literature, we were able to prepare an overview of the most important themes, which are, in our opinion, the main topics in the paediatric donation process. These themes provide essential elements for any future paediatric donation protocol.

Our analysis of the papers and electronic consensus statements by professional bodies enabled us to identify three interesting subjects for the discussion: paediatric donation after cardiac death protocols and policies, donor identification and referral to organ procurement organisations and approaching parents for donation.

Almost all papers reported on donation after cardiac death policies. Interestingly, paediatric protocols covering donations after brain death were not extensively discussed in the literature, which is surprising because most of the paediatric donations that take place follow brain death (1). It is remarkable that donation after brain death, donation after cardiac death and tissue donation are seen as separate topics and not as elements of a comprehensive donation protocol. In fact, tissue donation was not explicitly addressed in the literature, but was only mentioned a few times as a possibility. In our view, most of the aspects of a paediatric donation protocol are uniform for all types of donation and one comprehensive protocol would be helpful as this would make knowledge easily available to all stakeholders and optimise practice. We feel that this would be particularly true for identifying donors, making referrals to organ procurement organisations and approaching parents for donation.

The palliative care for potential donors depends on the type of donation. The policy statements and expert panel reports were in line with our view and call for the standardisation of paediatric donation policies and processes (9,19).

The first step in the donation process is to identify potential donors in the NICU or PICU, as appropriate referral of potential donors is likely to increase organ donation rates (9,10).

Accepted Article

However, no standardised indications and restrictions for potential paediatric donors were found in the reviewed literature. The literature is not clear about who is responsible for identifying potential donors. Sarnaik (14) was the only author to indicate that any member of the medical team could make a referral of a potential organ donor. This opinion was supported by a survey of PICU staff in 2010 (24), which reported that they unanimously agreed that the responsibility for donor identification lay with a doctor. In addition, 79% of the nurses believed that nurses were also responsible and 45% said it was the role of the transplant coordinator. To conclude, it is important that both indications and restrictions for potential donors and the responsibility for identifying and referring potential donors are clearly determined in a protocol.

The next question is when professionals should approach parents about donation and which professional should be responsible for handling this sensitive topic. The existing literature evidently recommends that delivering bad news about the patient's condition and approaching parents about donation should be two separate processes (10,12-16,18-20). Most American authors recommended allowing organ procurement organisation professionals to approach the families and discuss organ donation with them (9,10,13,14). Authors from The Netherlands (16) reported that physicians were responsible for approaching and discussing donations with parents. Rodrigue et al (5) showed that donations were more likely to occur when a member of the child's healthcare team mentioned the possibility of donation than if it was first mentioned by an organ procurement organisation coordinator and they supported that distribution of responsibilities. Further discussions about donation should be led by professionals, namely organ procurement organisations or healthcare professionals that are knowledgeable about the donation process and they should make the parents feel supported in making the decision. Some differences in organ donor practices between countries will probably remain, but we recommend that clarification is needed in all situations and locations about who will first approach parents about donations and who could best support parents to make decisions about donation.

There are some limitations that need to be mentioned. First, we only included sources published in English and it is possible that papers and material published in other languages could have enriched our review. Second, the literature on paediatric donation protocols was very limited and there were very different study designs. As a consequence, we could not group the research papers according to common denominators and perform a proper literature review and we had to limit ourselves to a critical analysis of relevant sources in this overview.

CONCLUSION

Although the current overview was based on a small number of sources published in English, we concluded that our extensive search did not yield any comprehensive paediatric donation protocol. This was a remarkable finding, because international experts have repeatedly called for standardised paediatric donation policies. We recommend the creation of a comprehensive protocol to help professionals to provide an optimal donation process for all potential paediatric donors and their families. Optimising the donation process, with the help of such protocols, could reduce waiting list deaths and may help to train and prepare professionals to provide excellent care during the donation process. We recommend that further research should be conducted to investigate the need for more specific and detailed paediatric donation protocols for healthcare professionals working in NICUs or PICUs.

Abbreviations: NICU, Neonatal intensive care unit; PICU, Paediatric intensive care unit.

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CONFLICTS OF INTEREST: The authors have no conflicts of interest to declare.

REFERENCES

1. Eurotransplant International Foundation. Annual Report 2015. Available at:https://www.eurotransplant.org/cms/mediaobject.php?file=AR_ET_20153.pdf. (accessed October 18, 2016).
2. Kieboom JK, Siebelink MJ, Albers MJ. Heart valve donation in two small infants. *Eur J Pediatr* 2006 ; 165: 498-499.
3. Siebelink MJ, Albers MJ, Roodbol PF, Van de Wiel HB. Children as donors: a national study to assess procurement of organs and tissues in pediatric intensive care units. *Transpl Int* 2012; 25: 1268-1274.
4. Siebelink MJ, Geerts EA, Albers MJ, Roodbol PF, van de Wiel HB. Children's opinions about organ donation: a first step to assent? *Eur J Public Health* 2012; 22: 529-533.
5. Rodrigue JR, Cornell DL, Howard RJ. Pediatric organ donation: what factors most influence parents' donation decisions? *Pediatr Crit Care Med* 2008; 9: 180-185.
6. Bellali T, Papadatou D. The decision-making process of parents regarding organ donation of their brain dead child: a Greek study. *Soc Sci Med* 2007; 64: 439-450.
7. Weiss AH, Fortinsky RH, Laughlin J, Lo B, Adler NE, Mudge C, et al. Parental consent for pediatric cadaveric organ donation. *Transplant Proc* 1997; 29: 1896-1901.
8. Siebelink MJ, Albers MJ, Roodbol PF, van de Wiel HB. Het kind als donor. *Medisch Contact* 2007; 62: 1224-1226.
9. Martin DE, Nakagawa TA, Siebelink MJ, Bramstedt KA, Brierley J, Dobbels F, et al. Pediatric Deceased Donation-A Report of the Transplantation Society Meeting in Geneva. *Transplantation* 2015; 99: 1403-1409.

10. American Academy of Pediatrics. Committee on Hospital Care, Section on Surgery, and Section on Critical Care. Policy statement--pediatric organ donation and transplantation.

Pediatrics 2010; 125: 822-828.

11. Bratton SL, Kolovos NS, Roach ES, McBride V, Geiger JL, Meyers RL. Pediatric organ transplantation needs: organ donation best practices. *Arch Pediatr Adolesc Med* 2006; 160: 468-472.

12. Antommaria AH, Trotochaud K, Kinlaw K, Hopkins PN, Frader J. Policies on donation after cardiac death at children's hospitals: a mixed-methods analysis of variation. *JAMA* 2009; 301: 1902-1908.

13. Kolovos NS, Webster P, Bratton SL. Donation after cardiac death in pediatric critical care. *Pediatr Crit Care Med* 2007; 8: 47-49.

14. Sarnaik AA. Neonatal and Pediatric Organ Donation: Ethical Perspectives and Implications for Policy. *Front Pediatr* 2015; 3: 100.

15. Curley MA, Harrison CH, Craig N, Lillehei CW, Micheli A, Laussen PC. Pediatric staff perspectives on organ donation after cardiac death in children. *Pediatr Crit Care Med* 2007; 8: 212-219.

16. Siebelink MJ, Albers MJ, Roodbol PF, van de Wiel HB. Key factors in paediatric organ and tissue donation: an overview of literature in a chronological working model. *Transpl Int* 2012; 25: 265-271.

17. Mathur M, Castleberry D, Job L. Identifying potential heart donors among newborns undergoing circulatory determination of death. *J Heart Lung Transplant* 2011; 30: 389-394.

18. Harrison CH, Laussen PC. Controversy and consensus on pediatric donation after cardiac death: ethical issues and institutional process. *Transplant Proc* 2008; 40: 1044-1047.

19. American Academy of Pediatrics. Pediatric Organ Donation and Transplantation: policy statement: organizational principles to guide and define the child health care system and/or improve the health of all children: Committee on Hospital Care and Section on Surgery.

American Academy of Pediatrics. *Pediatrics* 2002; 109: 982-984.

20. Weiss MJ, Hornby L, Witteman W, Shemie SD. Pediatric Donation After Circulatory Determination of Death: A Scoping Review. *Pediatr Crit Care Med* 2016; 17: e87-e108.

21. Cowl AS, Cummings BM, Yager PH, Miller B, Noviski N. Organ donation after cardiac death in children: acceptance of a protocol by multidisciplinary staff. *Am J Crit Care* 2012; 21: 322-327.

22. European Society of Paediatric Neonatal Intensive Care. ESPNIC Standards for End of Life Care / About - European Society of Paediatric Neonatal Intensive Care - ESPNIC. 2017.

Available at: <http://espnice-online.org/About/ESPNIC-Standards-for-End-of-Life-Care>.

(accessed 20, 2017).

23. ODT National Health Service (NHS) UK. Paediatric care - ODT Clinical - NHS Blood and Transplant. 2017. Available at: <http://www.odt.nhs.uk/deceased-donation/best-practice-guidance/paediatric-care/#paediatricorgandonation>. (accessed October 20, 2017).

24. Stavel M, Akinsoji Y, Latifi S. PICU staff attitude towards organ donor identification and donation after circulatory death. *Arch Dis Child* 2011; 96: 700.

Appendix 1: Literature Search Strategies

Original search strategy

Pubmed

("Tissue and Organ Procurement"[Mesh] OR "Tissue Donors"[Mesh] OR "Terminal Care"[Mesh:NoExp] OR donation*[ti] OR donor*[ti] OR organ don*[tiab] OR heart don*[tiab] OR liver don*[tiab] OR kidney don*[tiab] OR lung don*[tiab] OR end-of-life[ti])

AND

("Child"[Mesh] OR "Infant"[Mesh] OR "Adolescent"[Mesh] OR child*[tiab] OR pediater*[tiab] OR paediatric*[tiab] OR infan*[tiab] OR adolescen*[tiab] OR teenager*[tiab] OR youth[tiab] OR infant*[tiab] OR neonat*[tiab] OR newborn*[tiab])

AND

("Clinical Protocols"[Mesh] OR "Guidelines as Topic"[Mesh] OR "Guideline" [Publication Type] OR systematic[sb] OR systematic review*[ti] OR guideline*[ti])

EMBASE

('organ donor'/exp OR ((organ OR tissue OR heart OR liver OR kidney* OR lung*) NEXT/2 (donor* OR donation*)):ab,ti)

AND

('adolescent'/exp OR 'child'/exp OR child*:ab,ti OR pediater*:ab,ti OR paediatric*:ab,ti OR youth:ab,ti OR adolescen*:ab,ti OR infan*:ab,ti OR kids:ab,ti OR neonat*:ab,ti OR newborn*:ab,ti OR teenager*:ab,ti)

AND

('practice guideline'/exp OR 'policy'/exp OR 'systematic review'/exp OR 'consensus development'/exp OR guideline*:ab,ti OR protocol*:ab,ti OR policy:ab,ti OR policies:ab,ti)

Adjusted search strategy

PubMed

("Tissue Donors"[Mesh:NoExp] OR "Tissue and Organ Procurement"[Mesh] OR ((donation*[ti] OR donor*[ti]) AND (organ[tiab] OR tissue*[tiab] heart[tiab] OR liver[tiab] OR kidney*[tiab] OR lung[tiab])) OR organ don*[tiab] OR heart don*[tiab] OR liver don*[tiab] OR kidney don*[tiab] OR lung don*[tiab])

AND

("Child"[Mesh] OR "Infant"[Mesh] OR "Adolescent"[Mesh] OR child*[tiab] OR pediater*[tiab] OR paediatric*[tiab] OR infan*[tiab] OR adolescen*[tiab] OR teenager*[tiab] OR youth[tiab] OR infant*[tiab] OR neonat*[tiab] OR newborn*[tiab])

AND

("Clinical Protocols"[Mesh] OR "Guidelines as Topic"[Mesh] OR "Guideline" [Publication Type] OR systematic[sb] OR systematic review*[ti] OR guideline*[tiab] OR protocol*[tiab] OR policy[tiab] OR policies[tiab])

Author	Publication year	Country	Design	Donation type
Antommaria et al (12)	2009	USA/Canada/ Puerto Rico	Mixed-methods analysis	DCD
Kolovos et al(13)	2007	USA	Review	DCD
Sarnaik (14)	2015	USA	Review	DBD DCD
Curley et al (15)	2007	USA	Qualitative study	DCD
Siebelink et al (16)	2012	Netherlands	Overview	DBD DCD
Martin et al (9)	2015	International	Panel report	DBD DCD
Committee on Hospital Care and Section on Surgery (10)	2010	USA	Policy Statement	DBD DCD
Mathur et al (17)	2011	USA	Prospective review	DCD
Cowl et al (21)	2012	USA	Qualitative study	DCD
Harrison et al (18)	2008	USA	Empirical study	DCD
Committee on Hospital Care and Section on Surgery (19)	2002	USA	Policy statement	DBD
Weiss et al (20)	2016	Canada	Review	DCD
United Kingdom (UK) National Health Service (NHS) Best practice guidance (23)	Accessed October 2017	UK	Electronic consensus statements	DBD DCD
European society for paediatric and neonatal intensive care society (ESPNIC) (22)	Accessed October 2017	International	Electronic consensus statements	DBD DCD

Table 1. Characteristics of included sources

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Author	Themes	Key findings
Antommara et al (12)	1. Identification and referral of potential donors	Clinical indications, minimum age restriction, minimum weight restrictions.
	2. Approach of parents and family	The decision to withdraw life-sustaining medical treatment separate from the decision to donate.
	3. Collaboration with the OPO	OPO personnel: obtain informed consent, evaluating the potential donor, and/or assisting in scheduling organ recovery;
	4. Informed consent	Minimum content for the informed consent process.(ability to withdraw consent at any time).
	5. Palliative care	Preclude medications with the intention to hasten death, support to the donor's family, the location, the family can be present at OR. Prohibit pre-mortem interventions to increase organ viability if they might cause harm or pain.
	6. Declaration of death	Specified criteria or tests for declaration of death (electrocardiogram (ECG) findings, pulselessness, apnea, and unresponsiveness). Waiting periods 2-5 min. Maximum time following the withdrawal of life sustaining treatment for organ recovery 60 -120 minutes.
Kolovos et al (13)	1. Identification and referral of potential donors	Early referral to the OPO will help determine whether the patient is a candidate for donation.
	2. Approach of parents and family	The option of DCD only after a decision to withdraw support was made.
	3. Collaboration with the OPO	OPO is a representative for DCD discussion.

	<p>5. Palliative care</p>	<p>Patients should receive comfort care measures that are unaffected by their potential donor status during the withdrawal process.</p> <p>Medications that preserve graft function should not harm the donor or hasten death and must be discussed with the family at the time of consent. Heparin is routinely administered before cardiac and some programs also administer vasodilators (phentolamine) or antioxidants (steroids, vitamin E, or N-acetylcysteine) to improve graft function.</p> <p>Families must be prepared for the possibility that if the child does not succumb to cardiac death within the allotted time, he or she cannot be a solid organ donor. Tissue donation may remain an option.</p> <p>The location of withdrawal of support will vary by the practical need. Family requests to be with their child at the time of death must be considered.</p> <p>Families should be prepared to leave their child quickly once death is declared, but they have the option to withdraw from the donation process.</p>
	<p>6. Declaration of death</p>	<p>After extubation, the attending physician monitors the patient for absence of pulse pressure by arterial catheter, heart tones, apnea, and unresponsiveness. 5-min observation period in children may to be prudent.</p>
Sarnaik (14)	<p>1. Identification and referral of potential donors</p>	<p>By the time the diagnosis of brain death is considered for a patient, the medical team should already have notified the OPO of the potential for organ donation.</p> <p>Any member of the medical team can make a referral of a potential organ donor.</p>
	<p>2. Approach of parents and family</p>	<p>“Decouple” the processes of declaration of death with discussion of organ transplantation.</p>

	3. Collaboration with the OPO	OPO approaching all potential organ donor families
	4. Informed consent	Informed consent for DCD.
	5. Palliative care	Therapies for comfort as indicated by standard end-of-life care. Withdrawal of support occurs at decided location. Care of the body should be according to the family's wishes.
	6. Declaration of death	Brain death can be diagnosed in term newborns defined as 37 weeks gestational age or greater. Declaration of circulatory death: waiting period usually 2–5 min. Delayed cessation of circulation: period is usually 60–120 min.
Curley et al (15)	2. Approach of parents and family	The decision to WLS should be distinctly separate from any consideration of DCD. Who would be responsible for informing parents of the possibility for DCD; specifically, is it a physician's responsibility at end of life or the responsibility of organ procurement agencies?
	4. Informed consent	Informed consent, pre-mortem procedures and parents should be informed that they could change their mind at any time if DCD became unbearable.
	5. Palliative care	Parents would require full disclosure about how their child's death would evolve with DCD and without DCD.
	7. Staff education	Staff members recommended that their education be supplemented with ongoing staff support and debriefing.
Siebelink et al (16)	1. Identification and referral of potential donors	Donor identification. The role for the intensive care team in signalling donation is underexposed.

	2. Approach of parents and family	Communication with the parents in 3 steps: breaking bad news, discussing donation and decisions about donation. Good communication influences donation willingness positively.
	3. Collaboration with the OPO	Some authors promote bringing in OPOs, whereas others emphasize the importance of attending physicians and nurses.
	5. Palliative care	Little attention was paid in the literature to the medical treatment of paediatric donors. Little is known about best practices regarding aftercare and the effects of the donation procedure on the family
	7. Staff education	We did not find remarks on existing educational programmes for professionals.
Martin et al (9)	<i>Recommendations</i>	Pediatric protocols should be routinely used where possible to standardize pediatric donation and management practices. Health authorities, professional organizations, and healthcare institutions providing care for pediatric patients should collaborate and promptly establish plans for development, introduction and implementation of standardized, best practice guidelines that can be adapted by local health systems.
	1. Identification and referral of potential donors 2. Approach of parents and family 3. Collaboration with the OPO 5. Palliative care 6. Declaration of death 7. Staff education	These should include guidelines for: recognition of potential donors; timely and accurate determination of death; provision of care to potential donors and their families; optimal management of the donor. Health professionals from all specialties and disciplines (e.g. nurses, physicians, physician assistants and allied health workers including neonatology, palliative care, anaesthesia, emergency medicine) who may be involved with care of potential or actual donors should be encouraged and enabled to access donation education.

Committee on Hospital Care and Section on Surgery (10)	1. Identification and referral of potential donors	Timely referral to OPOs can increase organ-donation rates.
	2. Approach of parents and family	The death notification and consent for organ-donation processes should be separated or “decoupled.” Every family should be given the opportunity for organ donation if it is medically appropriate. The decision to donate is one made by the family, not by physicians.
	3. Collaboration with the OPO	Collaboration with physicians, the health care team, and the OPO is important.
	4. Informed consent	The consent procedure for organ donation should be handled by a Trained professional.
	5. Palliative care	Organ donation is an integral part of end-of-life care.
	6. Declaration of death	Accurate and timely declaration of neurologic death is essential.
	7. Staff education	Education of staff should include medical, ethical, social, cultural, and religious issues related to the potential donor and recipient families.
Mathur et al (17)	1. Identification and referral of potential donors	NICU personnel do not would have to be familiarized with identification and referral of potential donors through education.
	2. Approach of parents and family 3. Collaboration with the OPO	Medical staff would have to collaborate with the OPO to evaluate medical suitability and a collaborative approach requesting the family for donation.
	5. Palliative care	Management of the potential donor may require changes in current practices or protocols. The location where withdrawal takes place may need to be customized depending on the distance between the NICU and the operating room.

Cowl et al (21)	5. Palliative care	Allocation of a private space near the operating room for patients' families; Liaison, for a child's family after the child has been taken into the operating room.
	7. Staff education	Debriefing process after each donation case with both the organ bank and PICU staff;
Harrison et al (18)	2. Approach of parents and family	DCD will be an option for some families, but none will be pressured to see organ donation as an obligation or expectation.
	4. Informed consent	Participating families will give genuine informed consent which includes a statement that parents can change their mind at any time in the process. They will be informed of the differences between the procedure of death, if child is going to be a DCD donor or not.
	6. Declaration of death	The child will clearly be dead, which implies no potential for cognition before organ removal takes place.
	5. Palliative care	Diversity in religious, cultural, and personal values will be respected.
Committee on Hospital Care and Section on Surgery (19)	2. Approach of parents and family 4. Informed consent	The death notification and consent for organ donation processes should be decoupled. The procedure for consent for organ donation should be handled by a trained professional.
	7. Staff education	Education of staff should include medical, ethical, social, cultural, and religious issues related to the potential donor and recipient families.
Weiss et al (20)	<i>Neonatal donors are not inherently different from other pediatric populations.</i>	

	2. Approach of parents and family	Consent for DCD should take place after and separate from the decision to WLST.
	4. Informed consent	<p>Minimum informed consent prior to DCD: precise methods of determining death, logistics of the process, what specific organs are and are not eligible for procurement, how palliative care would proceed.</p> <p>The consent can be withdrawn at any time, including after the determination of death.</p>
	5. Palliative care	<p>Providing optimal palliative care, including narcotics and other comfort medications, no medication can be given with the intent to hasten death.</p> <p>Families should be given the option to be present at the time of WLST and the determination of death.</p>
	6. Declaration of death	<p>Determination of death - diagnostic tests: the absence of heart sounds by auscultation, palpable pulse, and breath sounds were most common.</p> <p>Determination of death- diagnostic procedures: unresponsiveness, absent arterial pulse, and apnea.</p> <p>Wait periods after arrest of circulation, 2–10 min.</p> <p>Low-risk antemortem interventions such as heparin or bronchoscopy are acceptable.</p> <p>DCD will only occur if the time to death after WLST does not exceed 1–2 hours.</p>
ESPNIC (22)	1. Identification and referral of potential donors	Every child that may be potentially 'brain-dead' should be referred to organ donation services to enable parents to consider donation.

	<p>2. Approach of parents and family</p> <p>3. Collaboration with the OPO</p>	Discussion about organ donation with parents should occur with experts in donation. Collaborative discussion with the family by both PICU team and organ donation team together is preferred, though the organ donation team alone can approach if the ICU team agree this.
	5. Palliative care	Organ and tissue donation is a routine part of childhood end-of-life care for children.
	6. Declaration of death	Appropriate brainstem death (BSD) testing, in accordance with national guidelines.
<p>United Kingdom (UK) National Health Service (NHS)</p> <p>Best practice guidance (23)</p>	5. Palliative care	Optimisation of organs for transplantation. The optimisation care bundle for use on patients >37 weeks CGA - 15 years: Cardiovascular, respiratory, fluids and metabolic management thrombo-embolic prevention, lines, drugs, monitoring and investigations.
	6. Declaration of death	<p>The Academy of medical Royal Colleges (AoMRC) guidance to determine the death by neurological criteria in > 2months post term.</p> <p>The guidance Royal College of Paediatrics and Child Health (RCPCH) 2015 specifically to infants from 37 weeks gestational age (including corrected gestational age) to 2 months post term.</p> <p>Organ donation from infants with anencephaly — guidance from the UK Donation Ethics Committee</p>

Table 2. Themes and key findings